

Finding a Living Donor:

A RESOURCE GUIDE



Stony Brook **Medicine**



A Resource Guide to Finding a Living Donor

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The Benefits of Living Donation

Welcome to Stony Brook Medicine's Kidney Transplant Program. Our program was established in 1979, making it the oldest and most active program on Long Island. We have developed this guide to provide you and your loved ones with an understanding and education of the many benefits of a living donor kidney transplant, living donor transplant options, and ideas and ways to find a living donor.

Stony Brook Medicine offers you a highly specialized and experienced team to assist you. We have vast experience in working with both transplant recipients and living donors, and we would like to help make the process easier for you as you consider a living donor kidney transplant.

There are many benefits of receiving a kidney from a living donor:

- Living donor kidney transplant offers better outcomes for kidney patients. There is less chance of rejection and a greater chance of the kidney working longer.
- There is an improved quality of life for the recipient.
- Living donation can reduce your time on dialysis. Dialysis can take a toll on your health and life expectancy, restrict your diet and cause a great deal of stress on the whole family. Receiving a kidney transplant before needing dialysis is ideal and can happen with a living donor.
- It can help you avoid years of waiting for a deceased donor organ.
- A live donor kidney can last nearly twice as long as a deceased donor kidney.
- The living donor transplant can be done when both you and the donor are in the best physical and emotional health as possible. This leads to better outcomes.
- During a living donor transplant, the kidney will be placed into your body as soon as it is removed from the living donor. This means the kidney is deprived of blood supply for only a short time, and the transplanted kidney can work right away. A kidney from someone who has died is usually preserved for several hours or more before it is transplanted, and therefore, after transplant, it may take several days to work.

The Facts about Living Donation

Once you are aware of the basic facts about living donation, you will be in a better position to help others, who may be willing or interested in donating to you. Of course, your transplant team will be there to help you with difficult questions that may be asked by potential donors.

There are strict standards that the Kidney Transplant Center will follow in determining whether a person can be a living donor.

Some factors that may disqualify a person from being a living donor:

- Heart, liver, kidney, lung disease
- Recent history of cancer
- High blood pressure, in most cases
- Active infection
- Diabetes Mellitus
- Significant obesity, BMI greater than 36
- Substance abuse
- Proof of violation of federal law (illegal financial arrangement between donor and recipient)
- Proof of donor coercion (donor feels pressured to donate)
- Psychiatric condition not treated
- Mentally incapable of giving informed consent

The transplant team will also consider many other factors when deciding whether a person can be a living kidney donor.

Once a donor has been cleared by the transplant team to proceed with donation, it is important for you and the donor to be assured of the following facts:

- Medical costs related to the donor testing and donor surgery should be covered by the recipient's insurance.
- There are potential grants to assist with donor travel and lodging expenses for eligible patients.
- Donor surgery is usually performed laparoscopically which is "minimally invasive." In traditional "open" surgery, the surgeon uses a single incision to enter into the abdomen.
- Laparoscopic surgery uses several small incisions and one slightly larger incision to remove the kidney. This system allows the surgeon to perform the same operation as traditional surgery, but with smaller incisions.
- Compared to traditional open surgery, patients often experience less pain, a shorter recovery and less scarring with laparoscopic surgery.
- The donor is generally hospitalized for 2-3 days and recovery is expected to last 2-6 weeks.
- An Independent Living Donor Advocate will be assigned to each donor to protect their needs and interests during the testing and donation process.

Additionally, donors can expect to:

- Undergo a thorough education process by the transplant team about all of the risks and benefits of living donation.
- Go through comprehensive medical testing.
- Return to a normal lifestyle and live a healthy life with one kidney.
- Have medical follow-up at least once per year with their healthcare provider.
- Avoid contact sports such as football or boxing.
- Avoid Nonsteroidal anti-inflammatory drugs (NSAIDs), ie: Aspirin, Ibuprofen, Aleve, Motrin, Advil, etc.

It is important for you and your donor to understand that the donor's evaluation process is separate from the recipient's evaluation process, and confidentiality is maintained at all times. Our donor team focuses on the safety and well-being of the donor before, during and after surgery.

You, as the recipient, will not be given any information about your donor's evaluation or their medical status, unless the donor specifically informs us that we can share information. If your donor is deemed not eligible by the transplant team, you will not be informed why the donor cannot donate, unless the donor has agreed to share this information with you. This is not easy for many patients to understand, as they may feel anxious to move forward quickly. It is important to understand that the living donor's ability to donate safely from a medical, social, psychological and financial standpoint is the priority of the living donor transplant team.

In addition to learning about donation from us, we also suggest you and potential donors to speak to others who have already gone through kidney donor surgery. Your Transplant Coordinator can help you with this. We also recommend you visit the many education websites available to obtain information on living donation.

See Additional Tools and Resources section on page 12.

Living Donor Transplant Options

In the past, living donors needed to be close relatives of their recipients. This is no longer the case. A healthy person may be considered as a potential donor. Donors may be spouses, friends, co-workers, acquaintances or someone who does not even know the recipient. Sometimes complete strangers volunteer to help someone they hear about in need of a transplant. Other people come forward anonymously to donate a kidney to anyone on the waiting list, because they know there is a severe organ shortage.

The following ordered list should help you to find a suitable living donor. The transplant team can help you with this.

Related donor

Examples: mother, father, sister, brother, adult child

Unrelated donor

Examples: spouse, close friend, in-law, acquaintance, neighbor, co-worker, church friend, classmate

Altruistic donor - Blood Type Compatible

Example: someone that is not known to you, but has heard of your story and offered to donate

Alternative Programs for Recipients with Incompatible Donors

If your donor is not compatible with you, there are many options for you to be able to receive a living donor kidney transplant.

Alternative Living donor transplant options include:

Kidney Exchange Program – exchange or swapping of kidneys between incompatible recipient/donor pairs, so that all recipients receive a compatible transplant.

How To Find a Living Donor

Patients often ask us for advice on how to talk to family, friends and others about living kidney donation. Asking someone to donate an organ is a major decision and may create a variety of emotions for you, your family and the potential donor.

The following ideas and suggestions may be helpful to you when speaking about living donation with others.

Share your story with friends, family and community.

Many people are private or don't want to bother others with their medical issues. It is important to share your story. Don't assume that family and friends know about your situation. Let others know that you have kidney disease and that you came to the Kidney Transplant Center and were told that living donation would likely offer you the best outcome.

Talk with your family about who can be your spokesperson or 'champion'.

Often patients find it difficult to let others know of their need for a transplant. Consider identifying a spokesperson or 'champion' who can talk to others on your behalf about your need for a kidney transplant. This person may be a spouse or a close relative who is unable to donate for medical reasons, but wants to help you receive a living donor transplant. You and your spokesperson/champion can request a meeting with the transplant coordinator to learn the facts about living donation and ways to help you find a living donor.

Send a letter or e-mail about your need for a living donor to family and friends.

This is a great way to get the word out and share your story. Sample letters are included at the end of this guide for you to customize.

Let your community know about your need for a transplant and that living donation would likely provide you with the best outcome.

When family and friends are not available to donate, one of the best sources for living donors is usually a community group or religious congregation that you are involved in. Donors from religious groups tend to be highly motivated and often complete their donor evaluations and go on to successfully donate, either directly to the recipient or through kidney exchange if they are incompatible with their recipient.

Say 'yes' to someone who offers to learn about donation and be evaluated.

Many times recipients are hesitant to accept the offer of donation, especially from their adult children. Consider making an appointment for you and your adult children or other interested people to come to our scheduled workshops in order to learn the real facts about living donation. Don't say no without knowing the facts. Calling to learn more about donation does not obligate you in any way.

How To Find a Living Donor

Bringing up the topic of donation

For some people, it may be difficult to raise the topic of donation when speaking with family and friends, but in doing so, it will provide an opportunity for a personal discussion. It helps others to learn about your medical condition and need for a kidney transplant. You may want to set up a group or individual meeting to talk about donation, depending on your situation. For those who live far away, you, a family member or a friend may need to call, write or e-mail others to discuss your situation and available treatment options.

We also encourage you to bring someone close to you to attend your transplant evaluation appointment and class. This person can share information with potential donors.

Sometimes people may know that you are being evaluated for a transplant, but they haven't offered to donate. They may not even be aware that they can donate or maybe they just need information on how to proceed. If they want to learn about donation, an excellent place to start is by providing them with initial information like:

- **Stony Brook Medicine Kidney Transplant Center: (631) 444-2209**
- Our website at: **stonybrookmedicine.edu/transplant**

You can also obtain donor brochures from the transplant coordinators that can be given to those who might be interested in donating. Let them know they can contact us for more information about living donation. This does not obligate them in any way and remains confidential. We do not notify the recipient or any other person of potential donors without their permission.



What you might say during the discussion

Tell individuals that the transplant team advised you to meet with them to discuss living donation. You can emphasize the following facts about living donation:

- There is less chance of rejection
- Greater chance of the kidney working longer
- Improved quality of life for the recipient
- Can reduce your time on dialysis or avoid dialysis
- Can avoid years of waiting for a deceased donor kidney
- A live donor kidney can last nearly twice as long as a deceased donor kidney
- The transplant can be done when both you and the donor are in the best physical and emotional health possible. This leads to better outcomes.
- Donors are fully educated and screened carefully by the transplant team and all conversations are confidential
- No medical costs to donor
- The donor evaluation, surgery and initial donor follow-up appointments are covered by the recipient's health insurance
- Some donors may also be eligible for help with non-medical donor expenses, such as travel and lodging

Rather than ask someone to donate a kidney to you, encourage them to call Stony Brook Transplant Center to learn about living donation. A person can only decide if living donation is the right choice for them and their family once they have been fully educated.

Encourage them to include their spouse or significant other in the conversations with the Transplant Team. Share your feelings. This gives family members and other potential donors the opportunity to share their own thoughts in return.

CAUTION

It is extremely important not to place any emotional or psychological pressure on anyone to donate. Often it is not you (the recipient), but others who may be pressuring someone, perhaps unintentionally, to donate. If someone is feeling pressure to donate, this will be discussed during the donor evaluation, which may lead to them being disqualified as a donor.

Give it time

Don't expect potential donors to respond right away after you discuss donation with them. Some people make their decision immediately. Others need time to consider the many issues involved with donation and their own personal situation. Provide them with the information, support, space and the time they may need. It is important for them to comfortably discuss donation with their own immediate family, employer, or others involved in their daily lives.

Direct anyone interested in learning more about donation to contact the Living Donor Coordinator to discuss their questions or concerns at (631) 444-2209. Let them know that they can have a detailed and confidential conversation or meeting with our staff. We will never give information about a donor's discussion to recipients or others. Once a person decides to start the donation process, our transplant team will be there to assist that person through each step of the process.

Make a Public Plea

Some patients awaiting transplant may not be able to find a donor among their family and friends. Some may have success in finding a donor when they make their need publicly known. In such cases, a recipient, or the family members, may consider going to the general public to seek a donor. Some people have shared their situation and need for a transplant in local newspapers, community or church bulletins, on media (e.g. Facebook), or other Web sites to post their requests. While public pleas are becoming more common, they require great consideration and caution. If you plan to make a public request, we recommend that you first let the Kidney Transplant Center team know about your search. We can give you information and guidance that can help you with the process.



Basic guidelines when making a public plea for a living donor

- Consider starting your public plea with people that are connected to you in some manner such as friends, community/hobby groups or religious connections as they are more likely to give it serious thought and complete the donor evaluation process. Donors who live a significant distance away (outside the tri-state area) and who don't know you or share no connections to you are not as likely to donate.
- First, discuss your idea of creating a public notice with your transplant coordinator before you place such notices. We can help you make sure that any potential donors who respond to your plea are considered. Next, make sure that you have the permission to post a public notice with the organization involved (i.e. church, school, work, etc.)
- Direct any potential donors to Stony Brook Medicine's Transplant Center to complete a donor referral.
- Remember that all donors who are considered altruistic to you (donors who do not know you or do not share an emotional relationship with you) must be evaluated by Stony Brook Medicine's Transplant Center.
- You, or someone helping you with the search, may want to share basic information about yourself. How much information you want to share is a personal preference. It depends on your comfort level. You may want to discuss your ideas with your coordinator or social worker.
- You may want to include resources that potential donors can check to get more information about donation. This might include our Web or other national sites **stonybrookmedicine.edu/transplant**
- It is important to know and share with potential donors that the donor team will not inform or release any information about them to the recipient. We respect donor confidentiality at all times. It is up to the prospective donor to share information with the recipient if he or she wishes to do so.

CAUTION

- Stony Brook Medicine reserves the right to decline donors from certain websites or organizations, such as those that charge money for access to living donors.
- It may be difficult to determine the motivations of potential donors who are solicited in this way. Instead, patients have the most success finding a living donor when they keep their public pleas local to their own community and affiliations.

Additional Tools and Resources

Contact your Transplant Coordinator if someone is interested in donation

If you or anybody would like to learn more about living donation, please call the Stony Brook Medicine Kidney Transplant Center at (631) 444-2209. A transplant coordinator will provide detailed information. The coordinator will also have a confidential discussion with the potential donor. This information assists a person in deciding whether donation is right for him or her. There is no pressure or obligation to proceed and the discussion always remains confidential. If a caller remains interested, the coordinator will guide him or her as to how to proceed. The coordinator will also provide additional donor resources that may help the potential donor with their decision. We are always available to guide the potential donor throughout the process.

Helpful Websites

- National Kidney Foundation: www.living.donors.org
- American Society of Transplantation: www.ast.org
- Coalition on Donation: www.donatelife.net
- National Living Donor Assistance Center: www.livingdonorassistance.org
- United Network for Organ Sharing (UNOS): www.unos.org
- UNOS –Transplant Living: www.transplantliving.org
- Stony Brook Medicine: www.stonybrookmedicine.edu/transplant

For information specifically related to Costs/Finances and Legislation visit:

<http://www.transplantliving.org/livingdonation/financialaspects/legislation.aspx>



Sample Letter from Patient's 'Champion'

(Date)

Dear Family/Friends:

I am writing to (patient's first name) family and close friends, to let you know that (he/she) has been diagnosed with Chronic Kidney Disease. This means that (patient's first name) kidneys are failing or have failed. The kidneys help the body to filter blood and get rid of poisons, salt, and water. Without kidneys that work, people can become very sick.

(Patient's first name) doctors have told us that the ideal treatment for kidney failure is a kidney transplant. A kidney for transplant could come from a deceased donor (somebody who has died), but (patient's first name) would have to wait about 3-7 years for this kind of transplant. This would mean that (he/she) would probably have to be on dialysis for many years.

The doctors have said that the best type of kidney transplant is a transplant from a living donor (like a family member or friend). A transplant from a living donor also has the best chance of working for many years. Unfortunately, even though I would want to, I cannot donate one of my own kidneys to (patient's first name), because (explain reason and add any additional information about others in the immediate family who may have been ruled out as living donors).

During (patient's first name) evaluation at the Kidney Transplant Center, I learned that one of the best ways to help (patient's first name) was to become (his/her) 'Champion' and let those who are closest to (him/her) know about (his/her) kidney problems. I learned that in the U.S., there are over 100,000 people on the waiting list for a kidney. Each year, only about 11,000 of those patients are fortunate enough to get a kidney transplant from someone who has died and donated their organs. I am hoping that (patient's first name) will be able to find a living donor so that he/she can (avoid dialysis or come off of dialysis).

If you would like to learn more about living donation, the staff at (patient's first name) Kidney Transplant Center are available to talk with you confidentially at (631) 444-2209.

In closing, (patient's first name) has kidney failure, and any support you can offer to (him/her), is much appreciated. If (patient's first name) can get a kidney transplant from a family member or friend, that would be best for (his/her) health. Donating a kidney is a very personal decision that requires not only education about the risks and benefits, but also, thoughtful consideration and the support of loved ones.

Thank you in advance for your support.

(Most Sincerely or Fondly),

(Your Name)

Sample Letter from Patient Directly

(Date)

Dear Family/Friends:

I am writing to my family and close friends to let you know that I have been diagnosed with Chronic Kidney Disease. This means that my kidneys are failing or have failed. Without kidneys that work, people can become very sick.

My doctors have told me that the ideal treatment for kidney failure is a kidney transplant. A kidney for transplant could come from a deceased donor (somebody who has died), but I would have to wait about 3-5 years, or even longer, for this kind of transplant. This would mean that I would probably have to spend years on dialysis, where machines would clean my blood for me.

The doctors have said that the best type of kidney transplant is a transplant from a living donor. A kidney transplant from a living donor would mean that I wouldn't have to wait years for a transplant. A transplant from a living donor also has the best chance of working for many years. Unfortunately, there are no suitable donors in my immediate family.

During my evaluation at the Transplant Center I learned that in the United States, there are over 100,000 people on the waiting list for a kidney. Each year, only about 11,000 of those patients are fortunate enough to get a kidney transplant from someone who has died and donated their organs. I am hoping I will be able to find a living donor so that I can (avoid dialysis or come off of dialysis).

If you would like to learn more about living donation, the staff at my Kidney Transplant Center is wonderful and available to talk with you confidentially. You can call (631) 444-2209 if you wish to do so. Calling for information and education does not obligate you in any way. Your call and any information regarding your donation process is kept strictly confidential, even from me, unless you consent to share this information.

In closing, I wholeheartedly appreciate any support that you can offer to me, no matter how big or small. If I can get a kidney transplant from a family member or friend, that would be best for my health and my future. I realize that donating a kidney may not be right for everyone, or it simply might not be the right time. I also know that donating a kidney is a very personal decision, yet I hope that one of my family and friends will be able to help me.

Thank you in advance for your support.

(Most Sincerely or Fondly),

(Your Name)

Sample Public Plea to Community or Affiliation

My name is (First Name) and I have been diagnosed with Chronic Kidney Disease which means that my kidneys are failing or have failed. I will need a kidney transplant, as soon as possible, to avoid the need for lifelong dialysis treatments. (The next few lines should speak to your involvement with the community or affiliation to whom you are making the plea. For example, I have worked at (Name of Organization) for 15 years and have sought permission from Human Resources to publicize my situation. I am hoping that someone from (Name of Organization) will be able to help.

Or

I have been a member of (Name of church, synagogue or mosque) all of my life and have discussed my situation with (Name of Pastor, Rabbi or Iman) to obtain permission to share my situation with the congregation. I am hoping that someone from (Name of Organization) will be able to help.

Next, add a few lines about yourself, sharing as much or as little as you feel comfortable with. For example, I am 36 years old and married to my beautiful wife, (First Name). We have two young children, (Names and ages). I have just started dialysis which has been an enormous struggle for me and for my family, because of the many hours I must spend undergoing treatment. Also, I am feeling poorly much of the time which adds to the stress of my illness.

My doctors have told me that a living donor transplant is the ideal treatment option for me. Unfortunately, I do not have any possible living donors within my family and close friends which is why I am making this plea. I am in need of a donor who is in good health and willing to undergo further education and evaluation at the Stony Brook Medicine Kidney Transplant Center at (631) 444-2209. Attached, is a list of helpful resources and contact information. Thank you so much for your support.

About Stony Brook Medicine

Stony Brook Medicine integrates and elevates all of Stony Brook University's health-related initiatives: education, research and patient care. It includes six Health Sciences schools — Dental Medicine, Health Technology and Management, Medicine, Nursing, Social Welfare, and Pharmacy & Pharmaceutical Sciences — as well as Stony Brook University Hospital, Stony Brook Southampton Hospital, Stony Brook Children's Hospital and more than 100 community-based healthcare settings throughout Suffolk County. To learn more, visit stonybrookmedicine.edu.

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